Between "the best way to deliver patient care" and "chaos and low clinical value": General Practitioners' and Practice Managers' views on data sharing

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ABSTRACT

Objective: In the UK, General Practitioners and Practice Managers are key to enabling health information exchange (typically referred to as 'data sharing'). This study aimed to survey GPs and PMs for familiarity, engagement with and perceptions of patient data sharing.

Methods: Cross-sectional survey. All 107 general practices in England's second largest Clinical Commissioning Group, Cambridgeshire & Peterborough CCG. Descriptive statistics; hierarchical logistic regression; thematic analysis.

Results: 405 (64%) responses were received – from 338 (62%) GPs and 67 (71%) PMs. Familiarity and engagement were highest for local frail elderly and end of life care projects (>76% had used). The greatest difference in use concerned the now suspended national *care.data* initiative: PMs had odds of reporting use 75 times higher than GP partners (95% CI 27 to 211). Patient confusion was the most pronounced challenge and improved coordination the most pronounced expected benefit. Frequency of discussions with patients varied with IT competence (OR 4.2 for most competent users relative to least, 95% CI 1.7 to 10.7) and clinical system (OR 0.3, 95% CI 0.1 to 0.5). Patient reservations were reported more frequently by respondents who rated their IT competence as highest (OR 3.3, 95% CI 1.5 to 7.6), perceived more data sharing challenges (OR for a 1-point increase in challenges perception score 3.4, 95% CI 2.1 to 5.6) and by PMs (relative to GP partners, OR 18.0, 95% CI 7.9 to 41.3).

Conclusions: Familiarity with and use of data sharing projects was high among GPs and PMs. Both their individual and organisational characteristics were associated with the reported frequency of discussions and patients' responses. Improved awareness of the impact of provider characteristics and attitudes on patients' decisions about data sharing may enhance the equity and autonomy of those decisions.

BACKGROUND

In a world of ubiquitous IT-connectivity and fragmented patient care, Health Information Exchange (HIE) is envisaged as the IT-backbone to the "seamless integration" of health and social care services. The interest in it is enormous, as well as its expected benefits:[1-4] improved clinical decision making enabled by accessing a more complete longitudinal patient record;[5,1,6] improved coordination and continuity of care;[7-9] reduction in duplicate investigations[5,10-15] and hospital admissions;[5,14-19] improved patient safety[20] and enhanced experience, involvement and empowerment;[1,21] efficiency gains[22] and cost-savings.[11,14,15,23-26] The number of HIE initiatives is rapidly growing. For instance, a 2012 US survey found that 1,398 hospitals (30%) and 23,341 ambulatory practices (10%) were participating in 119 operational HIE projects, in comparison to 14% of hospitals, 3% of practices and 75 projects two years earlier two years earlier.[27]

Few systems, however, achieve the advanced and easy to-use-functionalities represented in visions for mature HIE.[24,28,29] The challenges of development, implementation uptake and sustainability are significant; the findings about outcomes are often disappointing.[2, 22, 24, 27, 30-39] A recent systematic review[24] suggests that HIE tools are used to a limited extent, typically in between 2% to 10% of patient visits, and that their impact on outcomes is largely unknown beyond HIE "probably reduces emergency department usage and costs in some cases".

In the UK, the 2013 Information Governance Review[1] introduced a new IG principle concerning "data sharing" (the preferred term for HIE locally): "the duty to share information can be as important as the duty to protect patient confidentiality". Improved patient data sharing is high on the National Health Service (NHS) agenda, a priority in key documents outlining its direction, such as the "Five Year Forward View",[40] "Personalised Health and Care Plan 2020",[41] "General Practice Forward View",[42] and in recent announcements of "unprecedented" NHS investment.[43] It is also concurrent with a broader drive towards increasing service integration.[44] In the UK, general practice is the setting where the primary patient record is held and clinical IT use is best embedded. As of 2016, 98% of General Practitioners (GPs) are using an electronic medical record in daily practice routinely.[45] GP and Practice Manager (PM) engagement with data sharing projects is thus crucial to progress in the field. No similar survey addressing familiarity, engagement with and perceptions of data sharing amongst UK GPs and PMs has been published. To our knowledge, the only directly comparable study is of PMs and primary care providers in the state of Michigan, US.[46]

The survey was part of a research-evaluation study of the Cambridgeshire & Peterborough Project for Data Sharing in End of Life Care (the C&P Project), initiated in 2012 as an Electronic Palliative Care Coordination System (EPaCCS) project.[47] Its core questions were:

1) What are GPs' and PMs' self-reported levels of familiarity with and use of different data sharing tools?
2) How do GPs and PMs perceive the benefits and challenges of patient data sharing?
3) What are GPs' and PMs' perceptions of patients' attitudes to data sharing?
4) What respondent characteristics are associated with 1-3 above?

The survey aimed to inform the work of the C&P Project team and other local decision makers involved in health IT projects by providing evidence on GPs' and PMs' knowledge, use and views on data sharing. By co-constituting the context of the C&P Project implementation, these were also seen as elements of mechanisms to be used in explaining the project outcomes within the broader research-evaluation study. Finally, the survey aimed to provide a snapshot of views on data sharing in UK general practice. While being a localised snapshot, it was developed with considerations for methodological transferability and the hope of motivating similar work in an area where expectations, promises, investments, efforts and vested interests are at exceptionally high levels, while rigorous research is scarce.

The study was carried out in England's second largest Clinical Commissioning Group, Cambridgeshire & Peterborough CCG, covering a population 0.86 million.

METHODS

Survey design and contents

We designed a survey on the basis of 1) the literature on HIE and Health Information Technology (HIT) implementation; 2) discussions at meetings of the C&P Project team; 3) discussions with members of the study Lay User Group; and interviews with project developers and stakeholder group members. Over 30 individuals (health professionals, IT staff, commissioners, managers, CCG communications officers, etc.) provided comments on survey versions, including four GPs and four PMs who piloted it. The final GP and PM surveys were largely identical, with some rephrasing and tailored questions (see GP version in Appendix 1, Supplementary file). Box 1 outlines the data sharing initiatives enquired about.

Box 1: Data sharing projects

1. **Summary Care Record** – an electronic record which contains information about medicines, allergies and adverse reactions and is available for over 96% of the population of England.
   http://systems.hscic.gov.uk/scr/patients/what
   http://www.hscic.gov.uk/article/6476/Summary-Care-Record-rolled-out-to-community-pharmacists

2. **eDSM (the Enhanced Data Sharing Model)** – a model of data sharing introduced in Aug 2013 in the dominant clinical IT system in the area, which resulted in a widespread campaign for consenting patients.
   http://www.digitalhealth.net/news/28231/tpp-rolls-out-new-sharing-model

3. **Frail, Elderly and High Risk Patients/ Multidisciplinary Team (MDT) project** – a local project using a standardised, detailed template (for data entry) and "view" (for read-only access) to create a shared care summary for frail, elderly or high risk patients, with a core aim of reducing unplanned hospital admissions. Highly prominent and incentivised at the time of the survey.

4. **End of Life Care Project, Cambridge** – a local project using a template and view to create a shared care summary for patients believed to be approaching the end of their life. An EPaCCS (Electronic Palliative Care Coordination System) solution. Highly prominent and incentivised in some areas at the time of the survey.

5. **End of Life Care Project, Peterborough** – a local project initiated prior to the Cambridge one, using a slightly different template but the same view and based around a Palliative Care Coordination Centre. The two projects were fully integrated after the survey was sent out.

6. **Medical Interoperability Gateway** – one of the pre-eminent commercial data sharing solutions in the UK, not available in the study area at the time of the survey.
   http://www.healthcaregateway.co.uk/products

7. **Urgent Care Dashboard** – a local project representing, at a practice level, unscheduled care contacts and admissions for the practice patients.

8. **Care.data** – a national project of the UK Government for extracting data from the records of all GP practices, using a default opt-in model. Led to a media outrage as a result of concerns about confidentiality and potential commercial uses of the data. Later suspended.

9. **Unscheduled care summaries** – locally standardised views for use in out of hours and emergency settings, including the End of Life Care Summary, Health & Care Summary and Plan, and Medical Problems and Drugs view.

We investigated the relationship between responses and nine independent variables:

- practice clinical IT system
- GPs' perceived competence in using it
- Caldicott (information governance) Guardian status
- professional role
- years of experience
- gender

- Local Commissioning Group (LCGs are largely independent sub-units of a Clinical Commissioning Group, there are eight LCGs in the Cambridgeshire & Peterborough CCG)
- time point of response (original survey, first or second reminder)
- efficiency of response (speed of returning the survey).

Information about the first five variables was solicited in the questionnaire and added subsequently about the remainder.

Sampling

A pre-existing database of GPs, PMs and practice addresses held by the team was updated with information from practice websites, the national NHS Choices website, and contacting practices. Information about the practice clinical IT systems was provided by the CCG IT team. Over time, staff numbers remained reasonably stable, but individuals changed frequently: for instance, a phone-in exercise 6 months after finalising the database, in August 2014, found that 69 of the GPs and PMs we had sent letters to had moved on. Flowchart 1 (Appendix 2, Supplementary file) details the changing GP and PM populations. We use 542 GPs, 95 PMs and 637 total as denominators in calculating response rates, to include all individuals who were sent the original survey letter and were still in their practices as of August 2014, as well as individuals who had left the practice but returned the survey.

Survey administration and context

The first mailing in April 2014 comprised a paper copy of the survey with an accompanying cover letter and freepost reply envelope. Each survey had a unique alpha-numeric code, which participants could use to complete the survey online and which we used to identify non-respondents. This code was subsequently cut off by an administrative assistant (SSB). Reminders were sent in May and August, in both cases about 2 weeks after the last response had been received. The first reminder included a “no further reminders and reasons for non-response” slip for those declining to participate and the opportunity to enter a prize draw of 3 x £100. The final reminder included a brief note handwritten by MP.

Data quality

Data were entered by SSB and MP, who checked each other's entries against the original questionnaires and minimal errors were corrected. Missing data in the nine independent variables (44% of respondents, 0.5% to 10% of variables) were accounted for using multiple imputation by chained equations [48-50] in Stata v13.1 (StataCorp, College Station, TX). Imputed outcome variables were not used in analysis [51]. Binary variables were imputed using logistic regression, while continuous and ordinal variables were imputed using predictive mean matching [52]. Results from the ten imputed datasets were combined using Rubin's rules.[48]

Analysis

Descriptive statistics and cross-tabulations aimed at preliminary exploration of associations were obtained in SPSS v22 (IBM SPSS Statistics). "Perception of benefits" and "perception of challenges" scores were computed, representing the mean sum of the values chosen for agreement/ disagreement with statements about the likelihood of a particular benefit/ challenge materialising. The benefits/ challenges were unweighted and normalised to a neutral point of 0 (the survey 'unsure' point was 3).

The association between nine respondent and organisational characteristics (see *Survey design and contents* above) and the following dependent variables were investigated: use of each of the nine data sharing tools included in the survey; frequency of discussions of data sharing with patients; frequency of two measures of perceived patients' endorsement of data sharing; and frequency of four measures of perceived patients' reservations about data sharing. Perceptions of benefits and perceptions of challenges scores were also included in the models for the latter three variables. Patient endorsement of data sharing was considered to be indicated by responses of "Yes, I agree" to data sharing and "I thought you were doing it already?!". Patient reservations were considered to be indicated by responses of "No, I do not agree" to having my data shared, "No, I am strongly opposed", "I am confused" and "Why are you asking me again?!". See Appendix 2 for four further higher level groupings of response options.

Exploratory analysis suggested substantial clustering in the answers given on related questions by each respondent. To account for this clustering, we used hierarchical logistic regression to investigate the association between respondent and organisational characteristic and the dependent variables. Initial models included interactions between each characteristic and the particular response, for example the particular data sharing tool. Interactions which were not statistically

significant (p>0.1) in any imputed dataset were removed as were terms relating to the timing of survey responses.

Free text responses were first coded in NVivo v9 (QSR International), with the final classification completed in Word.

RESULTS

Response rate and sample characteristics

Table 1 shows the response rate after each of the three mailouts. First responses were received in April 2014 and the majority of final responses in September 2014; a small number of replies continued until February 2015. Four surveys were completed online. Response rate was estimated at 63.6%: 62.4% of GPs and 70.5% of PMs. With the frequent changes of GP practice staff, this is likely to represent 57.3% of the current GP and 63.2% of PM populations (Flowchart 1, Appendix 2).

With regard to available population data (LCG and practice IT system), the sample was similar to the total population, with some differences observed in the proportions of users of two subtypes of one clinical system (EMIS Web and LV) for whom data sharing is less straightforward in the study locality (Table 2).

Table 1: Response rate by survey administration phase

Survey administration phase	Features of cover letter/ presence of incentives	Respondents number % of total responses within group			Minimal data respondents		
		Total	GPs	PMs	Total	GPs	PMs
Original mailout Apr 14	Name handwritten Signed by Primary Investigator and Research Associate	**40.2% (163)**	39.3% (133)	44.8% (30)			
1st reminder May 14	Prize draw Name handwritten Signed by PI and RA "no further reminders and reasons for non-response" slip added	**24.9% (101)**	24.0% (81)	29.9% (20)	**13**	11	2
2nd reminder Aug 14	Handwritten on headed study paper or small colour sheets	**34.1% (138)**	35.8% (121)	25.4% (17)			
Missing information		**0.7% (3)**	0.9% (3)	0			
Total		**100% 405**	100% 338	100% 67	**13**	11	2

Table 2: Sample composition and indicators of representativeness

	GPs		PMs		Total	
CHARACTERISTIC	**Respondents' value**	**Comparator: reference value or alternative measure***	**Respondents' value**	**Comparator: reference value or alternative measure**	**Respondents' value**	**Comparator: reference value or alternative measure**
No **%**	338 83.5% of survey respondents	542 85.1% of reference population	67 16.5% of survey respondents	95 14.9% of reference population	405 all survey respondents	637 reference population
ROLE SUBTYPE						
Partner	207 61.2%	151† 27.9%	NA		GPs only	
Salaried	73 21.6%	41 7.6%	NA		GPs only	
Locum	4 1.2%	9 1.7%	NA		GPs only	
Other	6 1.8%	3 0.6%	NA		GPs only	
Missing	48 14.2%	338 62.4%				
LOCAL COMMISSIONING GROUP‡						
LCG 1	97 29.0%	145 26.8 %	17 25.4%	25 26.3%	114 28.4%	170 26.7%
LCG 2	43 12.9%	58 10.7%	6 9.0%	9 9.5%	49 12.2%	67 10.5%
LCG 3	46 13.8%	76 14.0%	13 19.4%	17 17.9%	59 14.7%	93 14.6%
LCG 4	27 8.1%	45 8.3%	5 7.5%	9 9.5%	32 8.0%	54 8.5%
LCG 5	38 11.4%	57 10.5%	6 9.0%	9 9.5%	44 11%	66 10.4%
LCG 6	13 3.9%	25 4.6%	4 6.0%	4 4.2%	17 4.2%	29 4.6%
LCG 7	31 9.3%	71 13.1%	10 14.9%	14 14.7%	41 10.2%	85 13.3%
LCG 8	39 11.7%	65 12.0%	6 9.0%	8 8.4%	45 11.2%	73 11.5%
Missing	4		0		4	
CLINICAL IT SYSTEM						
SystmOne	241 71.3%	385§ 71.0%	52 77.6%	69 72.6%	293 72.3%	454 71.3%
EMIS Web	49 14.5%	61 11.3%	10 14.9%	9 9.5%	59 14.6%	70 11.0%
EMIS LV	38 11.2%	85 15.7%	3 4.5%	15 15.8%	41 10.1%	100 15.7%
Vision	7 2.1%	11 2.0%	2 3.0%	2 2.1%	9 2.2%	13 2.0%

** We use 'reference value' to mean a highly reliable comparison measure, usually taken from the whole population of interest. We use 'alternative measures' to mean comparators derived from an alternative sample. They may be less reliable than the survey values, but are the only comparator we can currently offer (source indicated). Alternative measures are in grey.

† Information from practice websites, as collected for the original database of all local GPs and PMs (Feb 2014). In the majority of cases (62%), information about partner status was not provided.

‡ LCG 1 – CATCH, LCG 2 – CamHealth, LCG 3 – Hunts Care Partners, LCG 4 – Hunts Health, LCG 5 – Isle of Ely, LCG 6 – Wisbech, LCG 7 – Peterborough, LCG 8 – Borderline.

§ Data provided by the CCG Primary Care Information Team, Sep 2014 update.

	GPs		PMs		Total	
CHARACTERISTIC	**Respondents' value**	**Comparator: reference value or alternative measure***	**Respondents' value**	**Comparator: reference value or alternative measure**	**Respondents' value**	**Comparator: reference value or alternative measure**
Changing or missing	3					
SELF-REPORTED IT COMPETENCE						
No	338	542	67	95	405	637
Familiar with basic functions	73 21.6%	NA	NA		GPs only	
Competent user	189 55.9%	NA	NA		GPs only	
Use more functions than most	59 17.5%	NA	NA		GPs only	
Missing	17 5.0%					
CALDICOTT GUARDIAN (IG) STATUS						
Yes	60 17.8%	NA	13 19.4%	NA	73 18.0%	107** 16.8%
No	272 80.5%	NA	51 76.1%	NA	323 79.8%	530 83.2%
Not sure or missing	6		3 4.5%		9 2.2%	
YEARS OF EXPERIENCE IN ROLE						
0-4	37 10.9%	1†† 0.2%	28 43.1%	NA	65 16.0%	only GP comparator
5-9	60 17.8%	21 5.8%	9 13.4%	NA	69 17.0%	only GP comparator
10-19	104 30.8%	118 32.7%	15 22.4%	NA	119 29.4%	only GP comparator
20+	113 33.4%	221 61.2%	14 20.9%	NA	127 31.4%	only GP comparator
Missing	24 7.1%	181 33.4%	1 1.5%	NA	25 6.2%	
GENDER (externally added)						
Male	145 42.9%	235 43.4%	14 20.9%	19 20.0%	159 39.3%	254 39.9%
Female	160 47.3%	241 44.5%	47 70.1%	69 72.6%	207 51.1%	310 48.7%
Missing	33 9.8%	66 12.2%	6 9.0%	7 7.4%	39 6.6%	73 11.5%

** One for each local practice.

†† Alternative measure using information on graduation/ registration of GPs from practice websites. Suggests a different profile of local GPs than the study sample, with a much smaller number of doctors at the beginning of their careers. Information was missing in 33% of cases (vs. 7% in the study). It is possible that years of experience have been highlighted on websites for more experienced GPs as a way of reassuring patients of the care they will receive in a particular practice.

Descriptive findings

Familiarity with and use of data sharing tools

The majority of respondents have used or recognised all nine data sharing projects with the exception of the Medical Interoperability Gateway (MIG), which was unfamiliar to 81.2%. The most familiar and used tools were local projects addressing the needs of frail elderly patients (1.5% "never heard of" and 89.4% have used at variable levels) and End of Life Care patients (3.5% / 4.7% "never heard of" and 76.2% / 77.9% have used, for Cambridgeshire and Peterborough respectively). After the MIG, the second least familiar project was the national *care.data* initiative (unheard of by 30.9%, primarily GPs) (Table 3).

Table 3: Familiarity and use of data sharing tools

	"Never heard of"						"Responses indicating use"					
Data sharing project	**GPs**		**PMs**		**Total**		**GPs**		**PMs**		**Total**	
Summary care record	2	0.6%	0	0.0%	2	0.5%	188	55.6%	51	76.1%	239	59.0%
Enhanced Data Sharing Model	99	29.3%	3	4.5%	102	25.2%	106	31.4%	48	71.6%	154	38.0%
Frail elderly project	6	1.8%	0	0.0%	6	1.5%	298	88.2%	64	95.5%	362	89.4%
End of Life Care Project, Cambridge	10	3.8%	1	2.0%	11	3.5%	194	73.5%	46	90.2%	240	76.2%
End of Life Care Project, Peterborough	3	4.3%	1	6.3%	4	4.7%	56	80.0%	11	68.8%	67	77.9%
Medical Interoperability Gateway	283	83.7%	46	68.7%	329	81.2%	3	0.9%	5	7.5%	8	2.0%
Care.data	123	36.4%	2	3.0%	125	30.9%	40	11.8%	48	71.6%	88	21.7%
Urgent Care Dashboard	25	7.4%	0	0.0%	25	6.2%	208	61.5%	62	92.5%	270	66.7%
Unscheduled care summaries	59	17.5%	13	19.4%	72	17.8%	176	52.1%	48	71.6%	224	55.3%

Perceptions of benefits and challenges of data sharing

Overall, GPs and PMs saw both the benefits and challenges of data sharing as somewhat likely to materialise: means were 0.53 and 0.56 respectively (0 was the neutral point, range -2 to 2, SD 0.73 and 0.53). The challenges perceived as most pronounced were patients' confusion (mean 1.12) and the anxiety created by media coverage (1.03). The benefit perceived as most likely was improved coordination of care (0.96). The least expected benefit was cost reduction (- 0.01), Table 4.

Table 4: Perceptions of benefits and challenges of data sharing

Statements are ordered by mean value, normalised to 0 (0 is neutral, values between -2 and 0 correspond to the benefit/ challenge considered unlikely and/or not a concern and values between 0 and +2 correspond to the benefit/ challenge considered likely and/or a concern). The final column represents challenges in black and benefits in white for a quick overview of what takes priority in perceptions.

Potential benefit	Potential challenge	No	Mean and SD	
	Patients are confused	401	1.12 (0.87)	
	Media coverage has created anxiety	401	1.03 (0.81)	
Coordination of care ↑		400	0.96 (0.83)	
Work within broad MDT team ↑		399	0.79 (0.85)	
Clinical decision making ↑		400	0.78 (0.90)	
Work within immediate team ↑		398	0.73 (0.86)	
	Medical-legal issues	400	0.65 (0.88)	
Patient experience ↑		400	0.64 (0.91)	
Unnecessary interventions ↓		400	0.63 (0.87)	
	Information governance	397	0.59 (0.88)	
	Time constraints will limit sharing own data	401	0.53 (0.91)	
	Time constraints will limit using shared data	400	0.49 (0.90)	
	Information quality	397	0.40 (0.92)	
Avoidable admissions ↓		399	0.38 (0.94)	
Data re-entry ↓		399	0.31 (1.03)	
	Records will be getting too much attention	399	0.19 (0.98)	
	Data re-entry ↑	401	0.08 (0.96)	
Length of hospital stay ↓		399	0.03 (0.88)	
Costs ↓		399	-0.01 (0.96)	

Frequency of discussions about data sharing and patient response types

At the time of the survey, which coincided with intense work on several data sharing projects (see Box 1), 89.1% (361) of respondents discussed data sharing with patients “occasionally” or more frequently: 58.0% (235) “occasionally”, 23.5% (95)“on most days”, 7.7% (31) “on most weeks” and 7.4% (30) “not at all”.

The most frequently reported patient response was agreement to sharing: 59.5% (241) of respondents reported hearing that often or very often, followed by “I thought you were doing it already” (38.8%, 157), confusion (32.8%, 133), “Why are you asking me again” (19.5%, 79), and not consenting to sharing (12.6%, 51). Strong objection to sharing was the least frequently reported patient response (9.6%, 39).

Free text responses

While there were some highly positive comments (e.g. “the best way to deliver patient care”, “vital”), the great majority of free text comments were negative (“ill thought-out”, “a mess”, “complete chaos and low clinical value!”) or at least hesitant (“the crucial thing is who the data is

shared with and why"). Overall, extended negative comments did not challenge data sharing in principle, but expressed frustration with the ways in which particular initiatives have been set up and overlapped, in the context of unrelenting pressures in general practice (Appendix 2).

Logistic regression findings

IT-infrastructure

While locally data sharing is easier or only possible under the dominant system for five projects (Enhanced Data Sharing Model, the two End of life Care projects, one in each locality, the Frail Elderly project, and CCG health and care summaries), clinical system was found to be associated with use of the EDSM (Odds Ratio 0.03, 95% Confidence Interval 0.01 to 0.09), Cambs End of Life Care (OR 0.3, 95% CI 0.1 to 0.7), and Summary Care Record (OR 0.4, 95% CI 0.2 to 0.7) (Figure A1 B, Appendix 2).

Staff using the dominant system were more likely to have discussions about data sharing than those using alternative clinical IT systems (OR other vs SystmOne 0.3, 95% CI 0.1 to 0.5) (Table A1, Appendix 2).

Clinical IT system did not appear to be associated with the frequency of reporting patient endorsement of data sharing ($p>0.1$, Table A2, Appendix 2), but was associated with the frequency of different types of negative responses. Respondents from practices using the dominant system were more likely to report patients responding with "Why are you asking me again?!" (OR 0.3 for users of alternative systems, 95% CI 0.1 to 0.6). Respondents from practices using alternative systems were more likely to report responses of 'strongly opposed' (OR 2.5, 95% CI 1.0 to 6.1) (Table A3, Appendix 2).

IT and IG knowledge

GPs who perceived themselves as more competent in using their clinical IT systems were more likely to use data sharing tools. The main difference was between users who reported basic skills and the rest, rather than between competent users and advanced users (OR competent vs. basic skills 2.5, 95% CI 1.5 to 4.0; OR advanced vs. basic skills 4.0, 95% CI 2.1 to 7.7, Figure A1 F, Appendix 2).

More competent users were more likely to report frequent discussions about data sharing, with an apparent dose-response relationship (OR 2.2, 95% CI 1.0 to 4.5 for those who self-rated as

competent users and 4.2, 95% CI 1.7 to 10.7 for those who self-rated highest, Table A1, Appendix 2). No association was found between clinical IT competence and reports of patient endorsement of data sharing. However, advanced users were more likely to report patient reservations (OR 3.3, 95% CI 1.5 to 7.6) (Table A3, Appendix 2).

Caldicott Guardians were found to be more likely than respondents not performing this information governance role to use data sharing tools (OR 2.4, 95% CI 1.5 to 3.8, Figure A1 E, Appendix 2). Caldicott Guardian status did not, however, appear to be associated with frequency of discussions or patient response types.

Demographics

Women were more likely than men to use the End of Life Cambs data sharing tool (OR 2.9, 95% CI 1.3 to 6.4, Figure A1 A) and, more tentatively, the Frail Elderly and Summary Care Record (ORs 2.2, 95% CI 1.1 to 4.6, and 2.5, 95% CI 1.0 to 6.5, respectively). Gender did not seem to be associated with the use of the remainder of the tools, the frequency of discussions about data sharing, and patient response types.

Respondents with >=10 years of experience were less likely to use data sharing tools than those with 0-9 years of experience (OR 0.4, 95% CI 0.3 to 0.6, Figure A1 D, Appendix 2). Years of experience were not associated with frequency of discussions about data sharing or patient response types.

Organisational context

There was weak evidence of a difference in the use of data sharing tools by LCG, with different trends for different tools (p=0.02) (Figure A2, Appendix 2).

Role

PMs were more likely to use data sharing tools than GP partners, while non-partner GPs were typically less likely to use them (Figure A1 C, Appendix 2). The single largest difference was for *care.data*: PMs had odds of reporting use 75 times (95% CI 27 to 211) higher than GP partners. This may reflect differences in the scope of the question, as PMs were asked about their practice's involvement, while GPs were asked about their personal use.

There was weak evidence of differences in the frequency of discussions by role (p=0.04, Table A1, Appendix 2), with non-partner GPs having such discussions less frequently. However, PMs were more likely than GP partners to report patient responses of "I thought you were doing it already"

(OR 2.8, 95% CI 1.0 to 7.6) and much more likely to report patient reservations than GP partners (OR 18.0, 95% CI 7.9 to 41.3) (Tables A2 and A3, Appendix 2).

Benefits / challenges perceptions as an independent variable

Respondents' perceptions of the benefits and challenges of data sharing did not appear to have an impact on how likely they were to discuss data sharing.

There was weak evidence (p=0.055) that the frequency of reporting patient endorsement was higher amongst those with a higher perception of the benefits of data sharing. It did not appear to be associated with perceptions of the challenges of data sharing (p=0.89) (Table A2, Appendix 2).

The frequency of reporting patient reservations about data sharing was associated with a higher perception of the challenges of data sharing (OR for a 1-point increase in challenges perception score 3.4, 95% CI 2.1 to 5.6). It did not appear to vary by perception of the benefits of data sharing (p>0.1) (Table A3, Appendix 2).

Timing

The timing variables (phase – original mailout, first or second reminder, and efficiency of return of the survey) was largely unrelated to the nature of the responses received. There was a suggestion of a difference in the frequency of discussions of data sharing by timing of response (p=0.025), with those who responded after the first reminder less likely to discuss data sharing with their patients (see Table A1, Appendix 2).

DISCUSSION

To our knowledge, this is the first methodologically strong survey-based study of UK GPs' and practice managers' familiarity with, use and perceptions of patient data sharing, and one of only two in an international context (see below for comparison with the US study [46]). This is in spite of the growing number of data sharing initiatives, the policy commitment, and the key role of general practice in enabling them.

Summary and implications of key findings

Levels of engagement and their predictors

We found GPs and PMs to be familiar and engaged with data sharing projects, particularly with local CCG projects on frail elderly patients and end of life care, which were used, at variable levels, by over three-quarters of respondents. Professional role emerged as the strongest predictor of use of data sharing tools: PMs were typically more likely to use data sharing tools than GP partners, while non-partner GPs were typically less likely to use them. In its extreme, PMs had odds of reporting use of *care.data* 75 times higher than that of GP partners. The higher levels of PM use may reflect primarily the different scope of the question, with PMs asked about their practice's involvement and GPs about their own. Yet it may also suggest that certain data sharing projects have a low real or perceived clinical utility and end up being driven at an administrative level. The more restricted use of data sharing tools by non-partner GPs is also notable. It is unclear whether it indicates, for instance, time constraints (non-partner GPs appear more likely to work part-time) or a perception of them having a more limited role in leading the coordination of patients' care.

In contrast, clinical IT system was found to be a weaker predictor of use than expected. Advantages were detected for users of the dominant system, who, in the study locality, have easier access to more and richer data sharing tools, but these advantages were less pronounced than hypothesised. Workarounds are available for users of the alternative systems. More importantly perhaps, the challenges of action for users of the dominant system (e.g. asking for patient consent, finding time, recognising that limitations of service capacity may invalidate even the most carefully developed care plan) may be almost as problematic as the barriers to action for the rest. Claims about 'easier access' or 'more and richer tools' are also only relative. None of the current systems offers a truly integrated patient information flow. Psychological compensatory mechanisms may also be at play: one explanation of why users of alternative systems reported patients' strong opposition more frequently is that they are more attuned to perceptions that validate the choice of their practice clinical system.

Key benefits and challenges

Respondents perceived patient confusion and the anxiety created by media coverage as the most pronounced challenges of data sharing and improved coordination of care as the most likely benefit. Overall, they were most sceptical about benefits corresponding to hard outcomes and key priorities for the NHS (reduction of avoidable admissions, length of stay in hospital, and cost reduction). Robust evidence about the positive impact of data sharing, which is currently unavailable, appears more likely to persuade GPs and PMs of its benefits than powerful stories and visions. This hesitancy may, however, result in a self-fulfilling prophesy, since data sharing is likely to be effective only with a critical mass of committed users.

Discussions with patients and patient responses

Both GPs and PMs reported high levels of discussing data sharing with patients, with fewer than 8% not raising the topic at all, suggesting that patients are given opportunities to express their preferences. Agreement to have one's data shared and surprise that this is not being done were the most frequently reported patient responses. Reports of strong objection were the rarest. In comparison to previous literature, our findings suggested a new and strong analytic direction concerning the range of non-patient related factors associated with the frequency with which GPs and PMs discuss data sharing and the responses they receive. These factors included clinical IT system, professional role, GP clinical IT competence, and a respondent's perceptions of the challenges of data sharing. To a degree, they may stand for differences of context necessitating different decisions (e.g. the limited benefits of sharing through some clinical IT systems may shift the cost-benefit ratio for some patients). Nevertheless, questions arise whether patients are enabled to make truly autonomous decisions about their data and the direction of decisions when these are better informed. We found, for instance, that respondents who self-rated their clinical IT system competence as highest were over three times more likely to report patient reservations. One possible interpretation is that patients find the added detail and realism around data sharing anxiety provoking and/ or disappointing.

Comparison with existing literature

With regard to patient attitudes, here indirectly measured, our findings concurred with numerous studies and reports maintaining that most patients embrace data sharing for the purposes of direct patient care.[1,53-58] Beyond this specific subtopic, the only directly comparable peer-reviewed study we are aware of is from Michigan, US.[46] A 2013 EU report benchmarking deployment of e-health amongst General Practitioners, based on a survey of 9,196 GPs from 31 countries,[58] also contains some HIE-related evidence, although its scope is much broader. The Michigan study explored PMs' and primary care providers' (PCP) perceptions of barriers and benefits associated with Stages 2 and 3 in the "meaningful use" of electronic health records (EHR). It found much lower rates of self-reported electronic information sharing (23% for both sending and receiving) than the ones identified here. The EU report too found that only 10% of GPs interconnect with other professionals/organisations through a shared system.[58] In both cases, this is against a background of a lower EHR use (in the Michigan study, 68% of the 233 sampled practices have been using an EHR

for > 2 years in comparison; in the EU report, 52% of GPs used electronic records exclusively or primarily as their form of record storage; in this study, the levels were at 100%).

In terms of attitudes (Michigan study comparison only, perceptions of drivers and barriers explored at a broader e-health level in EU report), US respondents were much more positive than their UK colleagues about the expected impact of achieving Stage 3 of meaningful use, associated with intense data sharing. For instance, 86% of them agreed that this would improve their patients' treatment and 85% that it would help their patients overall. Similarly to respondents from our sample though, those from the US expected fewer improvements in harder outcomes, such as reducing hospitalizations (59%). The key barriers identified by the Michigan PMs and PCPs were difficulty sending and receiving information electronically, time constraints, and the complexity of the workflow changes, while their Cambridgeshire colleagues prioritised patient confusion and media anxiety. It is unclear whether this reflects primarily differences in the questions asked or differences in perceptions. It is also intriguing to what extent the more positive US attitudes reflect an earlier stage of EHR use and still unbroken illusions about their near-future functionalities, or other factors associated with, for instance, the current US health system context or culturally determined expectations of the future. More broadly, this leads to an important question about the relative explanatory power for HIE progress of generic diffusion of innovation phases vs. contextual and cultural differences.

Study limitations and strengths

The key limitations of the study arise from it being a self-report cross-sectional survey in a single locality, at a particular time period, and in the context of limited prior research. Standard limitations of survey methods are thus a pertinent consideration, such as concerns about cognitive biases and differences of reference points associated with self-reporting, impossible to eliminate ambiguity of wording, and limitations in identifying causal relationships and trajectories of change. For instance, anecdotal evidence from the broader study suggests that use of data sharing tools may have dropped after initial enthusiasm, indicating the importance of studying the uptake of project over time. In addition, as many of the parameters investigated have not been subject to similar research, the survey was a new tool building on very limited prior examples.

On the positive side, this is the first study exploring GP and PM's familiarity, engagement with and perceptions of patient data sharing in the UK and one with a high response rate. We also believe it to be the first study in the Health Information Exchange literature that demonstrates this level of

entanglement of attitudes to data sharing of those who ask and those who are being asked about data sharing. Finally, these are findings about a rich and dynamic period in the early history of data sharing initiatives in the UK, providing helpful baseline information against which to evaluate future developments.

CONCLUSIONS

In our world of IT over-connection and health care over-fragmentation, patient data sharing is here to stay and improve. The scarcity of high quality research on data sharing is a serious concern against a background of both over-optimistic discourse and sensationalist exposure of risks, and of an exponentially growing number of projects. Robust research on the variety of models and outcomes of data sharing is needed so that healthcare professionals' and patients' perceptions and practices are more strongly grounded in evidence. Further research in the direction of this study, of exploring users' perceptions of data sharing, is also crucial. When perceptions vary between "vital", "the best way to deliver patient care" and a "complete chaos and low clinical value", their capacity to drive different courses of action seems a given.

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Supplementary files: *Supplementary file – Appendix 1 – survey, GP version.pdf* and *Supplementary file – Additional data.docx*

Conflicts of interests: none

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